WORKSHOP REPORT

Implications of HIPAA's Administrative Simplification Provisions for Public Health and Health Services Research

Prepared by

The Lewin Group

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I. ACKNOWLEDGEMENTS

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Thanks are due to all of the individuals who participated in the January 23, 1998 workshop-planning meeting. (See Appendix A for a listing of participants and organizational affiliations) The workshop sponsors also wish to recognize the following individuals for their contributions to the workshop planning process: Marjorie Greenberg, Anne Elixhauser, Robert Davis, Lynnette Araki, Phyllis Doulaveris, Hetty Khan, Charles Rothwell, Jane Harman and Doug Williams.

The Lewin Group worked with workshop organizers to prepare background materials, develop the workshop agenda, facilitate the workshop, and prepare the final Workshop Report. The team, headed by Eileen Salinsky, also included Tom Mannle, Amy Andersen, David Rousseau, Dawn Bartoszewicz and Sara Cooper. The organizers acknowledge the skillful meeting planning and management provided by the staff of Native American Management Service under the direction of Karen Bray.

The organizers also greatly appreciate the contributions of the authors of workshop background materials and discussion drafts:

- "Health Insurance Portability and Accountability Act (HIPAA) Administrative Simplification (AS) Provisions: Reference Materials", prepared by The Lewin Group.

- "Issue Brief: Why are HIPAA Data Standards Important to Public Health?" prepared by Eileen Salinsky, The Lewin Group.

- "The Potential Impact of Data Standards on Health Services Research into Quality Measurement and Improvement," prepared by Anne Elixhauser, Ph.D., Center for Organization and Delivery Studies, Agency for Health Care Policy and Research.

- "Migration to National Standards for Public Health Data System: A Case Study of the New York Experience," prepared by Bob Davis, New York State Department of Health.

- "Benefits of Protecting Health Information Privacy," prepared by Lawrence O. Gostin, J.D., LL.D. (Hon.) and James G. Hodge, Jr., J.D., LL.M.

- "Engaging Public Health and Health Services Research in the Health Data Standards Development Process", prepared by Eileen Salinsky, The Lewin Group.

The Lewin Group has created a “HIPAA Workshop” section on their web site (www.lewin.com/hipaa/) for these discussion draft papers focused on HIPAA, along with background materials, panel presentation materials, a participant list, and important links to other relevant sites.

II. EXECUTIVE SUMMARY

On November 2-3, 1998, The National Center for Health Statistics of the Centers for Disease Control and Prevention, in conjunction with the Agency for Health Care Policy and Research and the National Committee on Vital and Health Statistics convened a workshop to examine the implications of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) on the practice of public health and health services research. The workshop, "The Implications of HIPAA's Administrative Simplification Provisions for Public Health and Health Services Research," brought together leaders in health statistics, research, and informatics to examine the challenges and opportunities presented by HIPAA. This workshop served as an important first step toward future efforts to organize public health and health services research input in the on-going data standards development and maintenance process.

The workshop utilized panel presentations to educate participants about HIPAA requirements for data standards, as well as the standards development organizations (SDOs) and content committees likely to have responsibility for maintaining these standards. These plenary sessions provided participants with the baseline information needed to explore HIPAA's implications in greater depth. Through break-out sessions and discussion groups, workshop participants explored the challenges and opportunities posed by HIPAA standards and other ongoing standards development processes and developed an agenda for future action. The workshop had two key purposes:

- to determine what objectives public health and health services research communities should accomplish with respect to the implementation of HIPAA's administrative simplification provisions and

- to develop a strategy for achieving those objectives.

A. Objectives Identified

During the first day of the workshop, presentations and break-out sessions were designed to examine the data standards needs of public health and health services research. These standards needs were divided into three broad categories: (1) administrative transaction standards (e.g., claims, claims attachments, and enrollment data), (2) public health data standards (e.g., disease reporting, vital statistics), and (3) standards related to privacy protections. Participants acknowledged that because all these standards are grounded in clinical information systems some degree of overlap exists.

- **Needs related to administrative transaction standards.** Workshop participants acknowledged that a thorough assessment of the proposed administrative standards was a difficult, time-consuming task that could not be completed during the workshop itself. Some of the participants came to the workshop with an in-depth knowledge of HIPAA's data-related provisions and had already begun assessing HIPAA's impact on public health and health services research. However, most participants felt that further study was warranted to fully assess the adequacy of the administrative standards from a public health and research perspective. Furthermore, concerns were raised that data standards are not currently defined in a manner that facilitates review by a non-technical audience.

Despite these obstacles, workshop participants identified a number of specific data elements that are important for public health and health services research, which are not currently included in the proposed standard for the claim transaction. Priority data elements included (1) Onset of secondary diagnoses for inpatient setting; (2) Race of patient; and (3) Primary diagnosis. Workshop participants acknowledged that further evaluation is needed to determine the costs and benefits of including these data elements in the administrative standards. Consensus was reached that public health and research needed to invest in evaluating and understanding the administrative data standards more fully and that their perspectives needed to be represented on the standards development organizations and content committees responsible for maintaining the standards.

- **Needs related to public health data standards.** Workshop participants acknowledged that administrative datasets are of limited usefulness for public health surveillance purposes. However, a great deal of discussion focused on using HIPAA as a means for accelerating existing efforts to improve the standardization of public health information. Many participants felt that HIPAA has served to focus wide spread attention on the need for administrative and clinical data standards and for improved electronic data capabilities. Participants generally concurred that this heightened awareness could be harnessed to support the standardization of public health surveillance data, as well as to revitalize the public health data infrastructure.

- **Needs related to privacy protections.** HIPAA's mandate for the development of federal privacy legislation emerged as an important theme throughout the workshop. Participants recognized the importance of privacy and confidentiality in ensuring participation in public health interventions. However, they also acknowledged that overly restrictive federal privacy protections could limit the appropriate use of health information for research purposes. Throughout the workshop, participants argued for increased participation of public health and health services research communities in debates on federal privacy protections. Because of the commitment to both privacy **and** research, public health and health services research communities play a potentially pivotal role in striking a balance between privacy concerns and the needs of researchers.

Based on these discussions, five critical objectives that emerged from the workshop's first day were to:

- Ensure representation of public health and health services research on standards development organizations (SDOs);

- Establish forums for achieving consensus within public health and health services research communities about data content standards, while establishing an organizational focal point for decisions;

- Further develop standards for public health data transactions (e.g., births, deaths, reports of diseases);

- Educate public health officials and researchers about HIPAA by specifically identifying the impact on the target audience; and

- Re-evaluate public health data reporting requirements and consider alternative, more efficient data collection mechanisms.

B. Action Strategies

The consensus objectives from day one provided the foundation for the action strategies and recommendations that participants developed in the workshop's second day. The most significant recommendation that emerged from day two was a call for the creation of a consortium to organize public health and health services research communities on data standards. Workshop participants agreed that a consortium could serve as a mechanism for coordinating ongoing representation of public health and health services research interests in HIPAA implementation and other data standards-setting processes. Participants acknowledged that public health and health services research communities need to collaborate and "speak with one voice" on data standards issues. The consortium would help educate public health and health services research communities and facilitate consensus.

Workshop participants recommended that a consortium be created to:

- Convene local, state, and national public health and health services research entities around data standards issues utilizing existing organizations to facilitate communication and disseminate information;

- Identify high-priority data needs that can be met through the HIPAA transaction and clinical standards, as well as other standard setting processes;

- Seek formal representation on data content committees. (e.g., National Uniform Billing Committee and National Uniform Claim Committee);

- Organize public health and health services research representation on standards development bodies. (e.g., Health Level 7 and X12);

- Educate public health and health services research communities about standards issues; and

- Participate in the efforts to assure continued access to health care information by public health and health services researchers, with the appropriate safeguards for confidentiality of individually-identified data.

Participants agreed that the workshop served as an important first step in mobilizing public health and health services research communities on HIPAA implementation and ongoing data standards-development. The workshop brought together individuals representing various constituencies within public health and health services research communities. Through the workshop, participants shared their perspectives on data standards and learned from each other. The process of information sharing between various perspectives was a critical element in the success of the workshop, supporting the education and priority setting goals of the workshop. Workshop participants unanimously acknowledged an ongoing and critical need within public health and health services research communities for widespread outreach about data standards and HIPAA. Without outreach, it will be very difficult to broadly engage public health and health services researchers on data standards issues.

Workshop participants were resolute in their recommendations for increased involvement of public health and health services research in HIPAA and data standards development. The concrete recommendations that emerged from the workshop have the potential to increase involvement and ensure that public health and health services research data needs are reflected in data standards. However, public health and health services research will only be successful if they commit the necessary financial and organizational resources. Workshop participants argued that unless public health and health services research communities are willing to commit these resources, there is little chance of integrating public health and health services data needs in data standards and ultimately benefiting from the standards.

Workshop participants recognized the important role of associations and federal agencies in supporting ongoing involvement of public health and health service research communities in data standards issues. The National Association of Health Data Organizations (NAHDO), the National Association of Public Health Statistics and Information Systems (NAPHSIS), and the Council of State and Territorial Epidemiologists (CSTE) were identified as critical players.

Participants also suggested specific steps that associations and federal agencies could take to encourage the involvement in HIPAA standards and ongoing standards development processes. These include:

- Committing financial and organizational resources to establish a consortium;
- Organize national, regional, and local conferences on HIPAA standards and public health and health services research;
- Develop working groups to analyze technical aspects of data standards in order to develop comments on proposed standards; and
- Produce journal articles on standards-related issues to publicize the importance of HIPAA standards for public health and health services research.

III. INTRODUCTION

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) introduced significant national reforms to the health insurance industry, with the intent of reducing variability across states. This legislation includes an often overlooked provision focused on improving the efficiency and effectiveness of the health care system through the establishment of national data standards and other requirements to facilitate the electronic transmission of health information. The current lack of standardization creates significant inefficiencies for providers who must maintain separate systems to accommodate inconsistent formats. HIPAA's "administrative simplification" provisions seek to reduce the data collection and reporting burden on health care providers and their billing services by standardizing both data content requirements and transmission formats for electronic data interchange (EDI).

In response to these requirements, the National Center for Health Statistics of the Centers for Disease Control and Prevention, in conjunction with the Agency for Health Care Policy and Research, and the National Committee on Vital and Health Statistics sponsored the workshop, "The Implications of HIPAA's Administrative Simplification Provisions for Public Health and Health Services Research," to allow participants to examine the challenges and opportunities presented by HIPAA and to assess how standards will likely affect the practice of public health and health services research. The HIPAA workshop served as an important first step toward future efforts to organize public health and health services research input on HIPAA implementation in particular, and in standards development in general.

A. Workshop Objectives and Format

The two main goals of the workshop were (1) to consider the implications of HIPAA for public health and health services research; and (2) to identify ways for public health and health services research to become more engaged and involved in the ongoing standards-setting process. Participants were asked to assess the proposed standards and identify:

- Modifications needed to support public health and health services research; and
- Mechanisms to increase participation of public health and health services research communities in data standards development.

The agenda for the workshop was structured to help workshop participants develop clear strategies for future action. (An agenda and a complete list of workshop participants are provided in Appendices B, and C, respectively.) Plenary and panel presentations allowed participants to gain more detailed information about HIPAA and data standards development processes, providing baseline information to assess HIPAA's impact on public health and health services research. Through facilitated break-out sessions, workshop participants examined data standards in more depth and developed specific proposals and recommendations. Workshop participants engaged in full-workshop feed-back sessions to consider specific recommendations and reach consensus on priorities for future objectives. At the end of the HIPAA workshop, participants agreed on clear consensus objectives to ensure that the priority information needs of public health and health services research are addressed in ongoing efforts to maintain standards.

The individuals who served as plenary speakers and panelists represented key public health and health services research constituencies affected by HIPAA: leaders in public and private

sector health statistics, research, and informatics. The speakers and panelists identified critical issues for workshop participants to examine more thoroughly in order to analyze the challenges and opportunities that HIPAA presents for public health and health services research. Plenary and panel presentations also served an important education function by providing participants with essential background information on HIPAA and standards development processes. While education about HIPAA and standards development was not the primary goal of the workshop, it was critical to creating a "baseline" of knowledge that enabled workshop participants to engage in more informed discussions and debates.

The remainder of this report summarizes each of the workshop sessions:

- **Understanding HIPAA'S Administrative Simplification Provisions** provided basic information on HIPAA and helped to ensure that all participants had a common understanding of the legislation.

- **Bringing Public Health and Health Services Research Data Into Compliance with HIPAA Standards: Challenges and Opportunities** identified the key ways HIPAA is likely to influence public health and health services research.

- **Prioritizing the Data Needs of Public Health and Health Services Research** explored the data standards needs of workshop participants and helped to establish a set of objectives to guide public health and research involvement in HIPAA implementation.

- **Building Partnerships and Establishing Strategic Alliances** examined the perspectives of potential partners who are likely to share interests similar to public health and health services research.

- **Understanding the Standards-setting Process: How Things Work** provided a primer on the workings of standards development organizations and content committee responsible for maintaining HIPAA standards.

- **Ensuring Effective Representation in Standards Maintenance Efforts** explored strategies for achieving the objectives identified in previous sessions.

IV. UNDERSTANDING HIPAA'S ADMINISTRATIVE SIMPLIFICATION PROVISIONS

The workshop's opening plenary session provided workshop participants with important background information on HIPAA's Administrative Simplification provisions and their implementation. This session laid the foundation for participants to explore specific strategies on data standards in more depth throughout the workshop and helped to ensure a common understanding of the legislation. Nationally recognized experts provided workshop participants with detailed information on the provisions of the law and the legislative and administrative implementation processes. Workshop participants were briefed on the two major components of HIPAA's Administrative Simplification Provisions: (1) national data standards for the electronic data interchange (EDI) of health information and (2) federal privacy and confidentiality protections for health information.

A. HIPAA Standards

William Braithwaite, a Senior Advisor in the Office of Assistant Secretary for Planning and Evaluation (ASPE) at the Department of Health and Human Services, provided workshop participants with an in-depth presentation on HIPAA's intent and on-going implementation. While working on Capitol Hill, Dr. Braithwaite helped write the Administrative Simplification provisions that were eventually included in HIPAA. In his role at ASPE, he assists in overseeing HIPAA's implementation.

The presentation gave workshop participants a basic framework of knowledge within which to consider the HIPAA's implications for public health and health services research. The following summarizes some of the most significant points of the presentation:

- The development and implementation of HIPAA's Administrative Simplification provisions has, and continues to be, an evolutionary process. Although the concept of data standards is clear and well accepted, the details of identifying and implementing those standards involves broad-based input, compromise, and negotiation. HIPAA's implementation remains a work in progress. Final rules have not yet been published and some issues, such as the unique patient identifier, are likely to remain unresolved for the foreseeable future.

- HIPAA standards involve multiple stakeholders in government and the private sector. HIPAA was expressly designed to reflect data standards developed by private sector organizations and its implementation has relied on an inclusive approach that encourages input. Dr. Braithwaite reported that the law itself specifically names a number of committees, standards development organizations (SDOs), and associations to advise the Secretary on the development of standards. These include the:

    - ♦ National Committee on Vital and Health Statistics (NCVHS),

There "has been an incredible effort of outreach and communication with the industry and an incredible effort by the industry to reach out and communicate with HHS to build consensus standards that do the best thing for all of us."

- National Uniform Claim Committee (NUCC),
- National Uniform Billing Committee (NUBC),
- American Dental Association (ADA), and
- Workgroup for Electronic Data Interchange (WEDI).

(Because final rules have not yet been issued, the precise nature of the respective roles and relationships of these organizations is still somewhat unclear.)

- It will be important for public health and health services research communities to be involved in SDO and content committee processes in order to ensure that standards reflect the data needs of public health and health services research. Public health and health services researchers have not been active participants in HIPAA standards implementation or on-going administrative standards development processes. There are a number of established mechanisms for input on standards. In terms of HIPAA implementation, SDOs and content committees will continue to be a central mechanism for input on standards. HHS's Notice of Proposed Rulemaking (NPRM) process also provides an opportunity for stakeholders to comment on proposed standards.

"Think about the future. Because every year, you will have a chance to provide your input to make the standards better as they evolve."

B. Privacy Protections

James Hodge, Jr. from Georgetown University Law Center served as the health privacy expert for the workshop. Although Mr. Hodge's presentation occurred on day two of the agenda due to scheduling considerations, it will be discussed in this section because it helped set a basic framework for workshop participants to consider the possible privacy implications for public health and health services research.

Based on the questions posed to the presenters, workshop participants were clearly concerned about federal privacy protections for EDI mandated by HIPAA. Workshop participants expressed concern about the possible effects of federal privacy protections on researchers' access to health information. They understood that restrictive privacy protections could prevent researchers from accessing and using certain health information. Several workshop panelists suggested that if legislation is enacted without the input of public health and health services research, access to health data for research purposes could severely limited.

1. Overview of HIPAA's Mandate for Federal Privacy Protections

Mr. Hodge gave workshop participants a brief overview of HIPAA's provisions related to federal privacy protections.

- HIPAA imposes an August 21,1999 deadline for Congress to enact federal privacy protections. If Congress fails to meet the deadline, the Secretary must promulgate regulations to protect the privacy of the information covered by HIPAA.

- The Secretary issued recommendations for the use of individually-identifiable health information to Congress on September 11, 1997.

- During the105th Congress, the Secretary's recommendations and a number of legislative proposals were widely debated. To date, Congress has failed to pass any legislation and will likely address the issue when it convenes in early 1999.

2. Proposals for Federal Privacy Protections

Workshop participants were presented with an overview of the key provisions in the administrative recommendations and various legislative proposals for federal privacy protections. Mr. Hodge suggested that public health and health services research communities have the potential to make significant contributions to a number of the central issues under debate, including the preemption of state privacy laws and researcher use of health information. The following summarizes some of these issues:

"[A]lthough there is a synergistic effect to privacy in public health, we must recognize that public health uses of information are probably extremely beneficial and [warrant exemption from restrictive privacy protections]."

State Preemption A number of proposed federal privacy bills include provisions preempting state privacy laws that have been enacted to protect the privacy of certain health information. (e.g., HIV/AIDS, mental health) Public health and health services researchers have an interest in preserving these state laws that protect the privacy and confidentiality of individuals with certain stigmatized conditions. Public health has long recognized the importance of the guarantee of confidentiality for encouraging participation of individuals in public health programs. Alternative proposals include compromise language to explicitly exempt state-passed laws protecting public health and communicable disease information from broad preemption of state law related to the privacy of medical information.

Researcher access to private health information is critical to public health and health services research outcomes. Additional restrictions on the use of private health information by researchers could unduly impede research. Mr. Hodge informed workshop participants about specific provisions in a number of federal privacy proposals that restrict what health information researchers can access and how they can use it. Some of the bills propose expanding current requirements for informed consent. Specifically, some of the proposals would require researchers to obtain informed consents every time the health information is used. Since public health and health services researchers often use private health information that has been collected previously for purposes other than the research project in question, obtaining informed consent for each use restricts researcher use of health information. Some argue that requiring researchers to obtain informed consent each time health information is needed would be impractical and costly, hindering important research. A single authorization obtained at the time of enrollment should offer reasonable protection for most research uses of private health information. Behavioral and biomedical research involving human subjects are already subject to more stringent regulatory protections within the Common Rule. [1]

1Sixteen federal agencies and departments have adopted uniform regulations, known as the Common Rule, to govern biomedical and behavioral research involving human subjects. Institutional Review Boards (IRBs) use criteria within the Common Rule to assess the anticipated risks and benefits of proposed

Increased input from public health and health services research constituencies might help ensure continued access to health information for research and public health purposes. Public health and health services researchers should educate the public and policy makers about their research and the important public benefit of protecting researcher access to and use of private health information.

Public health and health services research communities can play a role in striking a balance between researcher use of private health information and privacy concerns. Mr. Hodge suggested that public health and health services research communities should highlight the history that public health has maintained for protecting patient privacy while meeting public health objectives.

"If you recognize the three concepts of privacy, confidentiality, and security you realize that there is no way to ever maintain absolute privacy in data collection. Under the principle of data privacy, there will always be authorized users of [private health data]."

research. IRBs assess the possible physical harm, psychological harm, and social and economic harm to human subjects. (Institutional Review Board (IRB) Guidebook, 1993. Office for Protections from Research Risks – NIH, HIH Office of Extramural Research.

V. IMPLICATIONS OF HIPAA STANDARDS FOR PUBLIC HEALTH AND HEALTH SERVICES RESEARCH

This panel presentation provided workshop participants with an overview of the many different ways HIPAA is likely to impact public health and research. Panelists represented state, federal, and local perspectives. Workshop participants learned about the impact that HIPAA might have on existing data collection and reporting systems and what might be involved with transitioning systems toward compliance with data standards. Although there was not a lot of time for group discussion, the panel presentations prepared workshop participants to more closely examine the implications of HIPAA standards for public health and health services research through the afternoon break-out sessions. The following summarizes the pertinent issues for (1) health services research, (2) hospital discharge data systems, (3) national disease surveillance, (4) state disease surveillance, and (5) Medicaid.

A. Health Services Research

"[I]f we can't articulate exactly what it is that these personal identifiers will do for us and what will happen if we don't have them available…, it is very likely that any individually identified data could be restricted only to those organizations that collect the data."

Anne Elixhauser, with the Agency for Health Care Policy and Research (AHCPR), provided workshop participants with an overview of the benefits and challenges of using administrative data for health services research, particularly for research on quality of care. The benefits of using administrative data for health services research include low cost, large numbers of observations available, a multi-year time frame, lack of obtrusiveness, population coverage, comprehensiveness, and the ability to assess the effectiveness of services. However, the limitations are significant, including problems with the meaning, completeness, and accuracy of diagnosis and procedure data; lack of data linkages to observe outcomes outside the health care system under study; lack of comparability of data structures and definitions across data systems; limited clinical and outcomes data; and limited data on health plans and providers.

Dr. Elixhauser discussed HIPAA's implications for the use of administrative data by health services research. Standardization in general, and HIPAA data standards in particular, have great potential for making administrative data more useful to researchers. Dr. Elixhauser suggested that health services research take advantage of HIPAA standards to improve the content and structure of administrative data for research purposes.

Dr. Elixhauser reviewed some of the opportunities that HIPAA's standards might have for public health and health services research. Proposed standards for administrative data and other HIPAA standards not yet developed could address the problems of data quality and utility for research purposes.

- **Data Content**. The standardization of administrative data will certainly make data more useful to public health and health services research, addressing some of the problems related to inconsistency. Dr. Elixhauser suggested that researchers review proposed standards to determine if essential public health and health services research data elements

are included. She introduced some important data characteristics for possible inclusion in data standards. These include:

- ♦ Patient characteristics – race/ethnicity, socioeconomic status, and social support;
- ♦ Clinical characteristics – onset of diagnosis, "Do not resuscitate" orders, source of admission, time of admission, patient status, and birthweight; and
- ♦ Payer and provider characteristics – payer (health plan) type and provider information.

- **Clinical Accuracy.** HIPAA's provision of diagnosis and procedure code sets that cannot be modified will greatly enhance the clinical value of administrative data. However, standardization alone will not resolve the limitations in clinical information inherent in administrative data. Future enhancements that will greatly improve the research potential of administrative data include: the addition of clinical data elements generated during the process of providing services (e.g., laboratory and pharmacy data); the addition of outcomes data (e.g., patient-derived functional status measures); and the provision of linkages that will allow studies of care that crosses health systems (e.g., rehospitalization and construction of episodes of illness). HIPAA's provider and patient identifiers could facilitate linkages between administrative, enrollment, and clinical databases, giving researchers greater access to patient- and provider-level health information.

> ***"[R]esearchers' input really needs to be elicited and incorporated because the data serves so many needs beyond administration and we have to be able to articulate what those needs are and what research really contributes."***

Dr. Elixhauser argued that it is imperative that health services researchers take advantage of lessons learned by state and other health data organizations as they move towards standardization. Past innovations from these organizations should be incorporated into the data standard now. In addition, the input of researchers who use administrative databases should also be elicited and incorporated now and in the future because these data serve myriad purposes beyond billing, eligibility determination, and accounting. Furthermore, Dr. Elixhauser suggested that incentives could be used to encourage innovations in the future. Tremendous headway has been made in using adminsitrative data to measure the quality of health care services; it would be unfortunate if the gains of the past decade were lost as datasets are standardized without full recognition of their value for research and quality measurement. Linking administrative data, that is generated for the primary purpose of adjudicating claims and determining eligibility, with clinical data, as is currently being done in many managed care organizations, will increase the ability of researchers to use large databases for research into health care quality. Enhancing administrative data to provide more complete information about patients, the processes of care, and the outcomes of care will faciliate a better understanding of our health care system and how to improve it. Dr. Elixhauser cautioned that suggestions regarding changes in the data standards for administrative data need to be made with full cognizance of the costs of making these changes, not only the costs of revamping data systems currently in existence, but the costs of operating those data systems in the future.

B. Hospital Discharge Databases

Robert Davis, with the New York State Department of Health, reported on the standardization efforts of New York's hospital discharge database, the New York State Statewide Planning and Research Cooperative System (SPARCS). Mr. Davis highlighted some of the opportunities that national standards might present for public health and health services research.

"We need to establish need, and we need to establish why what we do is worthwhile from a cost point of view."

- **Benefits of Standardization.** Mr. Davis noted that until the early 1990's, SPARCS, like other state hospital discharge databases, used a proprietary state standard for the collection and reporting of health information. The use of unique state systems make it difficult to reconcile content and format reporting differences, limiting the usefulness of data for researchers. Standardization can address these problems and ultimately improve the quality of data available to researchers.

"HIPAA is really a starting place for us. HIPAA is an opportunity and a mandate. It is not a state mandate …but a federal mandate."

- **Importance of Compliance**. Hospital discharge systems, as well as many other public health entities, are not required by law to comply with HIPAA standards. Moving toward compliance can be a costly and difficult endeavor. Mr. Davis suggested, however, that the benefits of compliance, particularly the benefits for improved data quality, far outweigh the costs. Workshop participants were urged to take advantage of the federal mandate for consistent data standards and voluntarily transition toward compliance.

- **Use of the Claims Attachment for Public Health Information**. Mr. Davis suggested that the claims attachment could make the structure of HIPAA's administrative standards more useful for communicating public health information. Specifically, the claims attachment could be used to electronically transmit public health data elements such as race/ethnicity of patient and onset of diagnosis.

- **Development of Standards**. Standards development processes, including HIPAA standards, use consensus to develop standards that all stakeholders can agree upon. Workshop participants were urged to become more involved in standards development processes to ensure that public health and health services research needs become part of national consensus standards.

C. National Public Health Surveillance

Meade Morgan, with the Centers for Disease Control and Prevention (CDC), discussed some of the ways that national public health surveillance systems might be affected by HIPAA standards. Dr. Morgan's remarks shed light on how HIPAA standards might help streamline some of the complexities in current public health surveillance systems and improve the quality of data.

The lack of standards in public health surveillance systems makes data linkages virtually impossible. He argued that HIPAA standards hold the potential to improve public health surveillance systems, making data more reliable and useful.

"The whole process of retooling our surveillance systems and, more broadly, the way we do surveillance, is going to take a lot of time and effort … so that we can take advantage of these data that HIPAA promises to offer public health."

- **Involvement in Standards Development**. The CDC has been very involved in ongoing standards development. While the involvement of CDC has been critical to ensuring that public health interests are represented in standards, there is a great need for more involvement from public health and health services communities. Public health and health services communities should develop consensus on priority data elements for presentation to SDOs and others.

- **Privacy Concerns**. Dr. Morgan responded to the privacy concerns expressed by workshop participants. He reminded participants of public health's historical commitment to maintaining privacy and confidentiality in order to support participation in public health reporting, surveillance, and care services. Public health and health services researchers should consider strategies to ensure representation of public health interests in privacy debates. Public health should demonstrate how public health uses private health information appropriately **while protecting** privacy and confidentiality.

D. State Public Health Agencies

John Lumpkin, representing the Illinois Department of Public Health, described how state public health agencies might be affected by HIPAA standards. Dr. Lumpkin suggested that HIPAA's administrative standards can significantly benefit public health and health services researchers. Public health and health services researchers should use HIPAA administrative standards to catalyze the standardization of public health surveillance systems, in order to:

- ♦ Improve the utility of health information for public health purposes; and
- ♦ Raise awareness of the need for standardization of public health systems.

"HIPAA is very important to the public health system. It gives us greater access, potentially greater access, to data that is going to be very useful for us to take action and protect the health of people who we have the responsibility to protect."

- **Lack of Standards in Public Health Surveillance Systems**. Current systems of public health reporting are complex and conflicting and often require the use of multiple stand-alone terminals for computerized public health reporting. This complexity creates challenges for providers and institutions required to report information. Complicated public health reporting systems compromise access and quality of public health data.

"We need to set standards for our own public health systems. If we can do that, we can dramatically improve our public health systems and, most importantly, best serve the needs of people who we are charged to protect."

- **HIPAA's Potential for Public Health**. HIPAA standards have enormous potential to simplify public health surveillance systems and, consequently, improve the practice of public health. Dr. Lumpkin suggested that the use of Health Level 7-compliant data dictionaries in public health surveillance systems can create uniformity and improve data. Although the standardization of public health surveillance systems may be a more important issue for public health entities than HIPAA's administrative standards, Dr. Lumpkin argued that public health entities should not view involvement on public health standards and HIPAA standards as contradictory. In fact, involvement in HIPAA standards is essential to the development of public health standards. Involvement in the on-going development of HIPAA's administrative standards will not only help to ensure that they meet the data needs of public health, but these efforts can serve as a catalyst to raise awareness about the need for standardization of public health surveillance systems.

E. State Medicaid Programs

Stanley Nachimson, representing the Health Care Financing Administration (HCFA), gave workshop participants an overview of some of the data challenges that Medicaid programs currently face with the implementation of HIPAA standards.

- **Differences in State Medicaid Programs Compromise Data**. The programmatic differences in state Medicaid programs have negative implications for data. The federal and state administration of Medicaid results in 54 separate and unique Medicaid programs. Each state designs its own Medicaid program specifications – eligibility, benefits, and delivery systems – within certain parameters. The differences and the lack of standards make it very difficult to compare data beyond the state level. HIPAA standards could help improve data collection and reporting in Medicaid programs.

"Many of the state Medicaid programs have been using electronic data interchange for a number of years, but most are not using the [X12N] standards that we are proposing."

"[S]tandards, national standards, really give state Medicaid programs an opportunity to work with other state agencies, state public health agencies, [and] state mental health agencies."

- **Use of Local Codes Complicates HIPAA Implementation**. The use of local codes by state Medicaid programs further complicates data linkages. States often use local codes to capture information on waiver programs and policies mandated by legislation. The information collected through local codes cannot be easily incorporated in a national system like HIPAA because the codes have no relation to a national structure. The continued use of local codes by state Medicaid programs will make it more difficult to fully implement HIPAA standards. Possible solutions

include imposing a national coding structure for local codes or developing a translation mechanism for those codes.

VI. PRIORITIZING THE DATA NEEDS OF PUBLIC HEALTH AND HEALTH SERVICES RESEARCH

The morning panel presentations provided workshop participants with significant background information on HIPAA standards and their possible implications for public health and health services research. These presentations provided workshop participants with basic information needed to consider the HIPAA's specific implications for public health and health services research. In afternoon break-out sessions, participants were asked to prioritize the data needs of public health and health services research. Each break-out group was given the following charge:

- Assess proposed HIPAA transaction standards to determine how they address the information needs of public health and health services research and

- Determine what data elements need to be incorporated into data standards.

It became clear during the course of the workshop that such a task required a detailed and highly technical analysis of the data standards. While such an analysis of data content and format could not be conducted within the parameters of the workshop, break-out session participants explored some crucial issues affecting the future involvement of public health and health services researchers on standards issues. As a result of these important discussions, participants developed targeted objectives to guide the future steps of public health and health services research communities on HIPAA implementation and standards development in general.

Workshop participants were divided into three break-out session groups according to the following broad categories: public health, research, and data collection/management. Workshop organizers divided individuals into like-categories to encourage the development of consensus of individuals involved in similar work. Each break-out session group focused their discussion on critical issues to their specific group. Through these discussions, break-out session participants were able to develop some clear priorities for further discussion by the full workshop. The following summarizes the discussions of each group.

A. Data Collection and Management Group

The participants in this break-out session represented a diverse group of interests within the data collection and management community including hospital discharge data systems, NUCC, NUBC, CDC, Medicaid, etc. The discussion of the group focused on the education needs of public health and health services communities and highlighted the fact they did not generally feel prepared to conduct a rigorous evaluation of the proposed standards.

The complexity of administrative transaction standards presents a barrier to more active involvement of public health and health services research communities on standards development. The group discussed strategies to help encourage the involvement of public health and health services researchers in standards development. The following critical objectives were identified:

- Educate public health and health services research communities about standards;

- Develop data priorities for public health and health services research; and

- Develop a user-friendly data dictionary to help public health and health services research communities become more involved in standards development processes.

B. Research Break-Out Group

The participants of the research group represented individuals involved in research in a variety of settings including managed care, government agencies (e.g. AHCPR, CDC), academia, and foundations. The participants focused most of their discussion on the implications of privacy protections on future research.

A number of participants expressed concerns about how federal privacy protections might restrict researcher access to private health information. The lack of public knowledge about public health and health services research might contribute to restrictions being placed on researcher access. The following objectives were identified:

- Educate the public and policy makers about the value of public health and health services research, particularly the importance of using private health information.

- Demonstrate the public value of research in order to protect researcher access to health information.

There was considerable discussion among participants about the unique role that public health and health services research communities could play in the national debate on federal privacy protections. The group expressed the need for ongoing and increased participation of researchers in the development of privacy protections. An additional objective emerged from these discussions:

- Public health and health services research communities should work with other stakeholders including medical ethicists to develop criteria for protecting health information while balancing public health needs.

C. Public Health Surveillance Break-Out Group

The participants in the public health surveillance group represented diverse perspectives including state and local public health agencies, disease and immunization registries, and federal agencies such as CDC. This group debated the importance of focusing on the administrative data standards required by HIPAA, rather than addressing the standardization of public health surveillance reporting. The group widely acknowledged that administrative encounter data are of limited value for disease surveillance purpose. However, consensus was also reached that HIPAA is likely to prompt continued development of clinical information systems and the electronic patient record. This standardization of clinical information was seen as a critical catalyst for the continued development of electronic disease reporting and the standardization of public health surveillance systems. The group also concluded that public health should have a role in shaping the administrative transaction standards in order to optimize the usefulness of administrative encounter data.

The following objectives were identified:

- Improve and standardize public health surveillance systems.

- Continue to ensure data standardization efforts within public health are consistent with efforts to standardize clinical information (e.g., HL7).

- Increase public health's visibility in the SDOs and content committees responsible for maintaining the administrative transaction standards.

D. Consensus Objectives

Common themes emerged from the feedback of each break-out session group. Each group recognized the critical importance of increased involvement of public health and health services research in data standards. Participants used a voting process to reach consensus on a set of prioritized objectives. Workshop participants concluded that these objectives should guide the future work of public health and health services research communities on HIPAA data standards and other ongoing standards development. The consensus objectives demonstrate the scope of interests represented within public health and health services communities. The top five objectives that emerged from the workshop's first day were:

- Ensure representation of public health and research on standards development organizations (SDOs);

- Establish forums for achieving consensus within public health and health services research communities about data standards, while establishing an organization focal point for decisions;

- Further develop standards for public health data transactions (e.g., births, deaths, report of disease);

- Educate public health officials and researchers about HIPAA by specifically identifying the impact on the target audience; and

- Re-evaluate public health data reporting requirement and consider alternative, more efficient data collection mechanisms.

Exhibit I provides a summary of the relative rank participants gave to the full set of consensus objectives.

Exhibit I: Prioritization of Objectives

RANKING	OBJECTIVE	SCORE
1	Ensure representation of public health and research on Standards Development Organizations (SDOs)	4.58
2	Establish forums for achieving consensus within public health and research communities about data needs and standards and establish an organizational focal point for these decisions	4.16
3	Develop standards for public health data transactions (e.g., births, deaths, report of disease)	3.83
4	Educate public health officials and researchers about HIPAA by specifically identifying the impact on the target audience	3.77
5	Re-evaluate public health data reporting requirements and consider alternative, more efficient data collection mechanisms	3.73
6	Demonstrate the value and cost effectiveness of data for research and public purposes both to influence the standards development process and to inform the privacy debate	3.48
7	Review and critically evaluate the cost/benefit trade-off of proposed changes to the administrative data standards, including the following: • Onset of diagnosis • Race/ethnicity of Patient • Primary diagnosis • Source of payment • Functional status • Location of encounter • Educational level of patient	3.37 4.05 3.79 3.63 3.59 3.44 3.41 3.35
8	Develop a user friendly data dictionary of the content of the proposed administrative standards	3.36
9	Develop guidelines for data linkages	3.20
10	Identify the need for, and availability of, tools to assist in public health EDI (e.g., shareware translators)	3.12

VII. BUILDING PARTNERSHIPS AND ESTABLISHING STRATEGIC ALLIANCES

The second day of the HIPAA workshop began with a panel presentation addressing the use of strategic alliances and partnerships with other stakeholders to maximize the influence of public health and health services research on standards development. These presentations followed up on the previous day's discussion of core data elements for public health and health services research. Workshop participants recommended identifying partners who share common data needs in order to ensure that certain data elements could be captured through the standards. Panelists represented a variety of perspectives including the federal government, managed care, and health insurance. While these perspectives are important, there are arguably many more potential partnerships beyond these entities.

The panelists identified areas of convergence and divergence between public health and health services research and potential partners. Panelists suggested that convergence of research or clinical requirements could serve as the basis for the development of common data standards. Panelists challenged workshop participants to examine how their own data needs might intersect with the data needs of other entities. A number of the panelists argued that some of the most obvious potential partnerships could be developed with research entities within managed care organizations, pharmaceutical and biotechnology firms, hospitals, and academic institutions.

A. Federal Agencies Perspective

Blake Caldwell, the Acting Director, Office of Managed Care at CDC, provided workshop participants with an analysis of public health and managed care research needs. She presented examples of strategic partnerships between her own office and health care industry representatives and described how these collaborations could serve as models for developing partnerships around data standards. Dr. Caldwell challenged workshop participants to use HIPAA as an opportunity to develop ongoing strategic partnerships beyond public health and the health services research communities.

> ***"Public health has realized that we have to work at the patient level to really affect prevention and do the kinds of things that we want to do and that requires partnering with the people who are taking care of the patients."***

Dr. Caldwell noted that the data needs and data sources of public health and managed care organizations are virtually identical. Both are concerned with surveillance, disease monitoring, quality assurance, and research. However, the timeframe, context, and sample size are often different. Despite these differences, converging information needs set the stage for strategic alliances with managed care organizations and other providers. These alliances offer the potential to significantly strengthen public health and research's influence on the SDOs and content committees.

B. Managed Care

Richard Platt, the Director of Research at Harvard Pilgrim Health Care, suggested that managed care organizations are optimal laboratories for health services research because they have a defined population, demographic information, clinical information, and resource utilization information. Managed care research represents a unique intersection of public health and clinical medicine, offering opportunities for strategic partnerships. He noted that managed care research and public health research priorities are often overlapping.

"[R]esearch communities that are based in managed care organizations are natural allies for public health and health services research communities."

Data linkages between managed care organizations or other entities are complicated given the existing information infrastructure. HIPAA standards and improved data linkage opportunities have the potential to expand public health and managed care research opportunities. Managed care researchers and public health and health services researchers should work together to define the data content in proposed standards or add data elements where necessary.

Donald Parsons, the Executive Director for Health Care Policy Development at The Permanente Federation, concurred that managed care researchers and others stand to gain a great deal from HIPAA standards through expanded access to data, improved ability to link data, and more complete information. Managed care research projects often reflect public health research priorities and can facilitate collaboration between managed care and other researchers. Examples of specific managed care research projects include:

- A vaccine study demonstrating the effectiveness of pnemococcous vaccine in preventing meningitis, sepsis, and pneumonia in infants;
- A social HMO demonstration project aimed at keeping frail elderly in their homes and preventing or delaying institutionalization, saving Medicaid dollars and utilizing Medicare dollars more effectively; and
- A study looking at the use of allergy evaluations within the management of asthma.

"Consistent data and uniform data will allow for collaborative research across data bases and across organizations."

Widespread collaboration between managed care researchers and other researchers continues to be hindered by obstacles including the lack of a unique patient identifier, privacy concerns, and proprietary attitudes toward information. All of the panelists agreed that the potential research benefits of data standards can only be realized if researchers continue to have access to health data. An overly restrictive federal privacy law could have devastating results for researcher access to health information.

C. Health Care Industry

Kathleen Fyffe, the Federal and Regulatory Director for the Health Insurance Association of America (HIAA), provided workshop participants with an overview of the implications of HIPAA standards on the health care industry. On behalf of HIAA, Ms. Fyffe serves as a member of the NUCC, NUBC, and NCVHS.

"I look at HIPAA as a way to greatly increase the amount of automated business transactions through electronic data interchange and that will ultimately help to reduce administrative costs."

While the routine use of electronic transactions has increased within the health industry, the lack of standardized formats for electronic transactions is problematic. Approximately 400 different formats for health care claim transactions are currently in use, adding unnecessary costs to health care transactions. By requiring the use of standardized formats for administrative transactions, HIPAA would improve the efficiency and cost-effectiveness of health care transactions.

Ms. Fyffe also noted that health information privacy concerns will continue to affect the implementation of HIPAA standards. Public concern about the use of private health information may ultimately prevent the implementation of HIPAA's unique patient identifier. Ms. Fyffe noted that the recently enacted omnibus spending bill prevents HHS from allocating any funds to promulgate or implement the unique health identifier. She urged public health and health services research to become more actively involved in the on-going privacy debate.

D. Participant Discussion

Panelists provided workshop participants with a greater understanding of the implications of HIPAA standards on potential partners and their use of health care data. Participants gained a better understanding of the marked similarities between public health and health services research and managed care research. Panelists suggested that these similarities, and similarities with other stakeholders, could be leveraged to increase the influence of public health and health services research interests on standards development.

There was clearly significant interest in discussing opportunities for developing partnership. Workshop participants discussed ways that public health and health services researchers could leverage their influence by developing linkages with other entities with similar interests. There was notable interest among participants in exploring ways to create strategic partnerships around surveillance and disease monitoring issues. The obvious similarities between public health and managed care research and health data on these issues can facilitate the development of partnerships on HIPAA standards issues. It was suggested that HIPAA standards could be used to increase the use of EDI for public health and surveillance information and, by working in partnership with health plans and providers, improve the accuracy and quality of available data.

Panelists suggested current research collaborations between public health, federal agencies, and managed care organizations could serve as the foundation for developing partnerships on HIPAA standards development. Workshop participants discussed a number of possible activities that public health and health services research communities and other research partners could undertake to influence HIPAA standards, including:

- Sponsoring joint meetings on standards-related issues comprised of national associations representing health services research, public health, managed care, and other researchers;

- Publishing journal articles and letters to the editor on the common data standards needs among researchers; and

- Submitting joint comments on proposed HIPAA standards and other standards development processes, highlighting the common data needs of public health, health services research, and other entities.

VIII. UNDERSTANDING THE STANDARDS-SETTING PROCESS: HOW THINGS WORK

SDO and content committees will have an on-going role in maintaining the proposed HIPAA transaction standards. HIPAA explicitly defines roles for many of these organizations in the on-going implementation of HIPAA standards. Throughout the workshop, participants learned that public health and health services researchers have been underrepresented in these transaction standards development processes. Most of the work to date has been driven by industry and focused on maximizing the efficiency of the transactions. The primary intent of HIPAA's administrative simplification provisions is, in fact, to improve and simplify the electronic transmission of health information. Industry concerns about creating additional information requirements were recognized.

A panel of experts presented workshop participants with detailed information on SDOs and content committees involved in standards development. The panelists all had significant experience with SDOs and content committees, providing workshop participants with a comprehensive overview representing federal agency involvement, Health Level 7, ASC X12N, NUCC, and NUBC. Panelists reminded participants of the role that SDOs and content committees play in advising HHS throughout the HIPAA implementation process. They also noted that SDOs and content committee processes will serve as mechanisms to revise and improve national data standards.

The panelists identified ways in which public health and health services research data needs have been represented in SDOs and content committee processes. They noted that until now, however, there has not been active participation throughout the public health and health services research communities. Panelists challenged workshop participants to become more involved in SDOs and content committee processes in order to ensure that public health and health services research needs are reflected in HIPAA standards.

A. Federal Role in Standards Development

Karen Trudel, Senior Technical Advisor at the Health Care Financing Administration (HCFA), oversees the review of comments to the NPRMs issued on HIPAA standards. She gave workshop participants an overview of HHS's role in standards development in general and in HIPAA standards implementation in particular. Ms. Trudel noted that the future process for maintaining the proposed transaction standards is still somewhat unclear. The proposed rule for the transaction standards suggests that the SDOs (e.g., X12N, HL7), the existing content committees (e.g., NUBC, NUCC) and the Department of Health and Human Services will all play a role in future revisions of standards.

"Access is obviously an issue. There is a need to make sure that organizations have a voice in this process."

B. ASC X12

"You have to explain why you want immunization lot number to a railroad locomotive engineer … You have got to explain why this is important to somebody who is not in your industry."

As the Data Standards Manager for the Utah Health Information Network, Dr. Jan Root works to increase the use of EDI of health information. She is a member of ASC X12N and a Co-Chair of the health care claims transaction work group, 837. Dr. Root gave workshop participants an overview of the ASC X12 process and the role it plays vis a vis HIPAA standards. She described the X12 process and the function of various committees, subcommittees, and workgroups in the development of consensus standards.

X12N represents the insurance subcommittee of X12. At the workgroup level, any participant in the meeting is allowed to vote. At the task group and subcommittees (X12N) levels, only members are allowed to vote. However, any person who attends X12 meetings is encouraged to participate in discussions. Active, vocal participation in the workgroups is crucial to influencing X12N deliberations because the recommendations of the workgroups carry considerable weight, and all decisions are governed by votes. Public health needs to increase its participation in these workgroups and build partnerships with other voting members to influence the standards development process.

C. Health Level 7

Ed Hammond is a Professor at the Duke University Medical Center and the chair of the Division of Medical Informatics. He is the past Chair of Health Level 7 and a member of the board, and past Chair of the Computer Based Patient Record Institute. Dr. Hammond gave workshop participants a summary of the HL7 standards development process. He emphasized the consensus nature of the process to encourage increased involvement of public health and health services research communities.

HL7 represents a broad variety of committees and workgroups which public health can participate in:

- HL7 committee (comprised of elected or appointed members);
- Workgroups;
- Technical committees;
- Special interest groups; and an
- Architectural review board.

"Specifically, what Health Level 7 has tried to do is create flexible, cost effective standards for interoperability among health care information systems."

HL7's membership is comprised largely of provider organizations and vendor organizations. Dr. Hammond noted that non-vendor organizations are required to outnumber vendor

organizations for balloting purposes, preventing vendor dominance.

D. NUBC

George Arges, the Senior Director of the Health Data Management Group of the American Hospital Association, evaluates and coordinates external health data reporting requirements for clinical, administrative, and financial transactions. He represents AHA on the Workgroup for Electronic Data Interchange (WEDI), ASC X12, and the NUBC.

The NUBC is a representative organization comprised of national provider organizations, national payer organizations, state associations, research, and public health. The NUBC creates and maintains uniform standards and claims such as the Uniform Bill-92 (UB-92). NUBC standards have mainly operated as voluntary standards. HIPAA offers an opportunity to use the force of federal law to mandate compliance with standards and significantly improve processes for EDI. NUBC works closely with state uniform billing committees to disseminate standards and solicit proposed revisions to existing standards. It has become more actively engaged in the establishment of data content standards for the other standard transactions particularly the claims attachment. Mr. Arges noted that public health should be involved in the on-going process to develop standards for the claims attachment.

"Keep in mind that administrative simplification as part of the law is to reduce administrative cost of delivering the care and we need to recognize that this is not about throwing spaghetti on the wall to see what sticks and then keep that."

E. NUCC

Jean Narcisi is the Director of the Office of Electronic Medical Systems at the American Medical Association (AMA). She manages the AMA's internal and external activities related to EDI, clinical informatics, federal and state administrative simplification legislation, and the NUCC. The NUCC is co-chaired by AMA and HCFA and is responsible for developing the HCFA 1500. Together with HL7, NUCC also figures to play a large role in the determination of transaction standards for the claims attachment. The role of the NUCC is somewhat parallel to that of the NUBC except that it focuses on the non-institutional arena.

"The NUCC feels that the [standard] data set should really meet all requirements. If you have got requirements that need to be met, we need to hear from you."

The NUCC membership is comprised of key stakeholders affected by health care EDI including payers and providers. NUCC relies upon a formal protocol based on consensus. Each member of the NUCC is encouraged to work with their own internal constituencies to solicit feedback on proposed standards. The NUCC is considering expanding its membership. Participants were asked for their assistance in identifying critical public health and health services research constituencies for possible NUCC membership.

F. Workshop Participant Discussion

Due to time constraints, workshop participants were unable to engage in a question and answer session with panelists. However, participants found the panel presentations extremely valuable. Participants learned about the major players in standards development processes and the critical need for continued involvement of public health and health services research communities in standards development. Although the precise relationship between the various SDOs and content committees remains unclear, consensus was reached that public health and health services research needs to be active in each of these forums.

A number of participants acknowledged that the technical complexity of standards development information and processes will continue to present challenges to increased involvement of public health and health services research communities. Workshop participants discussed a number of strategies to increase broad-based participation of public health and health services research in SDOs and content committee processes.

IX. ENSURING EFFECTIVE REPRESENTATION IN STANDARDS MAINTENANCE EFFORTS AND PROMOTING WIDESPREAD PARTICIPATION IN THESE EFFORTS: RECOMMENDATIONS FOR NEXT STEPS

Through panel presentations and discussions, workshop participants learned about HIPAA standards, standards development processes, and strategies to build partnerships with other stakeholders. This information helped workshop participants consider ways to maximize the influence of public health and health services research communities on the development of national standards. Through the workshop, participants acknowledged the importance of ongoing education about HIPAA and standards development processes. Participants also acquired many of the tools that will be necessary to ensure ongoing participation in standards development.

Workshop participants agreed on a set of consensus objectives to guide the future involvement of public health and health services research communities in HIPAA implementation and ongoing standards development processes. The most significant consensus objective that emerged from the workshop was a call for the creation of a consortium to organize the public health and health services research communities on data standards issues. This consortium would serve as a mechanism for ongoing representation of public health and health services research interests in HIPAA implementation and other data standards-setting processes. The consortium would:

- Convene local, state, and national public health and health services research entities around data standards issues utilizing existing organizations to facilitate communication and disseminate information;

- Identify high-priority data needs that can be met through the HIPAA transaction and clinical standards, as well as other standard setting processes;

- Seek formal representation on data content committees. (e.g., National Uniform Billing Committee and National Uniform Claim Committee);

- Organize public health and health services research representation on standards development bodies. (e.g., Health Level 7 and X12); and

- Educate public health and health services research communities about standards issues.

The development of a consortium will require the commitment of considerable financial and organizational resources. Professional associations and federal agencies have an important role in bringing together the various constituencies within the public health and health services research communities through their own organizational structures and through the consortium. Associations and federal agencies can utilize existing conferences and regional networks to organize standards-related activities. The objectives developed through this workshop should serve as a first step toward developing future goals and activities to integrate public health and health services research data needs in national standards. Through the consortium and other follow up steps, public health and health services research communities can develop concrete strategies to mobilize public health and health services research communities around HIPAA implementation and ongoing standards development processes.

AGENDA
Workshop on the Implications of HIPAA's Administration Simplification Provisions for Public Health and Health Services Research

November 2 and 3, 1998
One Washington Circle Hotel, Washington, D.C.

Monday, November 2, 1998

8:00 am – 9:00 am	**Conference Registration**
9:00 am – 9:30 am	**Welcome and Introductions** *Edward Sondik, National Center for Health Statistics* *Marjorie Greenberg, National Center for Health Statistics*
9:30 am – 10:15 am	**Understanding HIPAA**
Plenary	This brief plenary session will provide an overview of HIPAA's administrative simplification provisions, standards setting organizations and their relationship to each other, the proposed Federal rules and the rule making process, and a summary of the input contributed by public health and health services research. *William Braithwaite, Office of the Assistant Secretary for Planning and Evaluation*
10:15 am – 10: 30 am	**Break**
10:30 am – Noon *Panel Discussion*	**Bringing public health and health services research data into compliance with HIPAA standards: Challenges and Opportunities** This panel discussion will explore the advantages and challenges faced by public health agencies and health services research organizations seeking to migrate to HIPAA-directed content and transaction standards. *Anne Elixhauser, Agency for Health Care Policy and Research* *Robert Davis, New York State Department of Health* *Meade Morgan, Centers for Disease Control and Prevention* *John Lumpkin, Illinois Department of Public Health* *Stanley Nachimson, Health Care Financing Administration* *Eileen Salinsky, The Lewin Group (moderator)*
Noon – 1:00 pm	**Lunch**

1:00 pm – 3:00 pm *Break-out Sessions*	**Prioritizing the data standards needs of public health and health services research** These break-out sessions will seek to develop realistic consensus on how proposed standards could be modified to better meet the needs of public health and health services research and to identify a prioritized set of objectives for future involvement in on-going standards maintenance efforts.
3:00 pm – 3:15 pm	**Break**
3:15 pm – 4:00 pm *Break-out Sessions*	**Prioritizing the data standards needs of public health and health services research (continued)** From 3:15 pm – 4:00 pm, break-out session participants will prepare a report on their deliberations to report back to the workshop as a whole.
4:00 pm – 5:00 pm *Plenary*	**Report of Break-out Sessions** A representative from each break-out group will report back to the workshop as a whole. Convergent data standards needs will be identified and prioritized.

Tuesday, November 3, 1998

8:00 am – 8:10 am **Review of Day 1 Proceedings**
Eileen Salinsky, The Lewin Group

8:10 am – 9:50 am *Panel Discussion* **Building Partnerships and Establishing Strategic Alliances**
This panel discussion will seek to identify opportunities for establishing common data standards goals and partnerships between public health and health services research and with managed care organizations, pharmaceutical companies, large purchasers, and others interested in monitoring health care quality and conducting outcomes research and technology assessment.
Blake Caldwell, Centers for Disease Control and Prevention
Richard Platt, Harvard Pilgrim Health Care
Donald Parsons, The Permanente Federation
Kathleen Fyffe, Health Insurance Association of America
Eileen Salinsky, The Lewin Group (moderator)

9:50 am – 10:15 am **Balancing Privacy Protections and Public Health Information Needs**
This presentation will begin with a brief discussion of the historical and current status of health information privacy law and the legal and ethical values on which they are based. The speaker will then discuss the need to balance the beneficial uses of individually-identifiable health information with privacy protections.
James Hodge, Jr., Georgetown University Law Center

10:15 am – 10:30 am **Break**

10:30 am – Noon *Panel Discussion* **Understanding the Standards Setting Process: How Things Work**
This panel discussion will describe the processes and timelines of the various standards setting organizations and identify some of the key realities facing public health and health services research as they begin to engage in these processes.
Karen Trudel, Health Care Financing Administration
Jan Root, Utah Health Information Network
Ed Hammond, Duke University Medical Center
George Arges, American Hospital Association
Jean Narcisi, American Medical Association
Eileen Salinsky, The Lewin Group (moderator)

Noon – 1:00 pm **Lunch**

1:00 pm – 3:00 pm *Break-out Sessions*	**Ensuring Effective Representation in Standards Maintenance Efforts and Promoting Widespread Participation in These Efforts** These break-out sessions will seek to design strategies for (1) maintaining representation on the standards committees, (2) ensuring that this organized input is broadly reflective of public health and research concerns, and (3) identifying responsible parties.
3:00 pm – 3:15 pm	**Break**
3:15 pm – 5:00 pm	**Reviewing Workshop Results** This concluding session will recap the major recommendations that emerged during workshop proceedings, identify unresolved issues, and clarify next steps.

APPENDIX A

Planning Meeting for a Workshop on Implications of HIPAA's Administrative Simplification Provisions for Public Health and Health Services Research January 23, 1998

Participating Organizations

Agency for Health Care Policy and Research (AHCPR)
Centers for Disease Control and Prevention (CDC)
Health Care Financing Administration (HCFA)
Health Resources and Services Administration (HRSA)
Office of Assistant Secretary for Planning and Evaluation (ASPE)
Alabama Medicaid Agency
American Hospital Association (AHA)
American Medical Association (AMA)
Association for Health Services Research (AHSR)
Association of State and Territorial Health Officials (ASTHO)
Association of State and Territorial Public Health Laboratory Directors (ASTPHLD)
Council of State and Territorial Epidemiologists (CSTE)
MEDSTAT Group
National Association of County and City Health Officials (NACCHO)
National Association of Health Data Organizations (NAHDO)
National Association of Public Health Statistics and Information Systems (NAPHSIS)
National Committee on Vital and Health Statistics (NCVHS)
National Committee for Quality Assurance (NCQA)
New York State Department of Health

Attendees

Delton Atkinson, NCHS/CDC
Judy Ball, AHCPR, ASPE
Rachel Block, HCFA
William Braithwaite, NCHS/CDC, ASPE
Jessica Briefer French, NCQA
Rosanna Coffey, The MEDSTAT Group
Robert Davis, New York State Department of Health
Phyllis Doulaveris, NCHS/CDC
Doug Drabkowski, ASTPHLD
Mark Epstein, NAHDO
Carol Friedman, EPO/CDC (by Envision)
Daniel Friedman, Massachusetts Department of Public Health, NAPHSIS, NCVHS
Jerry Gibson, CSTE
Jason Goldwater, NCHS/CDC
Marjorie Greenberg, NCHS/CDC
Jane Harman, NCHS/CDC
Joy Herndon, EPO/CDC
Denise Koo, EPO/CDC (by Envision)

Jennifer Madans, NCHS/CDC
Bob Mayes, HCFA
Mike Millman, HRSA
Sarah Mingledorff, Alabama Medicaid Agency
Meade Morgan, EPO/CDC
Stanley Nachimson, HCFA
Todd Omundson, AHA/NUBC
Gib Parrish, EPO/CDC
Donna Pickett, NCHS/CDC
Glenn Pinder, NCHS/CDC
Charles Rothwell, NCHS/CDC
Mark Segal, AMA, NUCC
Laverne Snow, Utah Department of Health, ASTHO
Edward Sondik, NCHS/CDC
Michael Stafford, AHSR
Marc Tomlinson, NACCHO
Doug Williams, NCHS/CDC

APPENDIX B

AGENDA

Workshop on the Implications of HIPAA's Administration Simplification Provisions for Public Health and Health Services Research

November 2 and 3, 1998
One Washington Circle Hotel, Washington, D.C.

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Plenary	This brief plenary session will provide an overview of HIPAA's administrative simplification provisions, standards setting organizations and their relationship to each other, the proposed Federal rules and the rule making process, and a summary of the input contributed by public health and health services research. *William Braithwaite, Office of the Assistant Secretary for Planning and Evaluation*
10:15 am – 10: 30 am	**Break**
10:30 am – Noon *Panel Discussion*	**Bringing public health and health services research data into compliance with HIPAA standards: Challenges and Opportunities** This panel discussion will explore the advantages and challenges faced by public health agencies and health services research organizations seeking to migrate to HIPAA-directed content and transaction standards. *Anne Elixhauser, Agency for Health Care Policy and Research* *Robert Davis, New York State Department of Health* *Meade Morgan, Centers for Disease Control and Prevention* *John Lumpkin, Illinois Department of Public Health* *Stanley Nachimson, Health Care Financing Administration* *Eileen Salinsky, The Lewin Group (moderator)*
Noon – 1:00 pm	**Lunch**

1:00 pm – 3:00 pm *Break-out Sessions*	**Prioritizing the data standards needs of public health and health services research** These break-out sessions will seek to develop realistic consensus on how proposed standards could be modified to better meet the needs of public health and health services research and to identify a prioritized set of objectives for future involvement in on-going standards maintenance efforts.
3:00 pm – 3:15 pm	**Break**
3:15 pm – 4:00 pm *Break-out Sessions*	**Prioritizing the data standards needs of public health and health services research (continued)** From 3:15 pm – 4:00 pm, break-out session participants will prepare a report on their deliberations to report back to the workshop as a whole.
4:00 pm – 5:00 pm *Plenary*	**Report of Break-out Sessions** A representative from each break-out group will report back to the workshop as a whole. Convergent data standards needs will be identified and prioritized.

Tuesday, November 3, 1998

8:00 am – 8:10 am **Review of Day 1 Proceedings**
Eileen Salinsky, The Lewin Group

8:10 am – 9:50 am *Panel Discussion* **Building Partnerships and Establishing Strategic Alliances**
This panel discussion will seek to identify opportunities for establishing common data standards goals and partnerships between public health and health services research and with managed care organizations, pharmaceutical companies, large purchasers, and others interested in monitoring health care quality and conducting outcomes research and technology assessment.
Blake Caldwell, Centers for Disease Control and Prevention
Richard Platt, Harvard Pilgrim Health Care
Donald Parsons, The Permanente Federation
Kathleen Fyffe, Health Insurance Association of America
Eileen Salinsky, The Lewin Group (moderator)

9:50 am – 10:15 am **Balancing Privacy Protections and Public Health Information Needs**
This presentation will begin with a brief discussion of the historical and current status of health information privacy law and the legal and ethical values on which they are based. The speaker will then discuss the need to balance the beneficial uses of individually-identifiable health information with privacy protections.
James Hodge, Jr., Georgetown University Law Center

10:15 am – 10:30 am **Break**

10:30 am – Noon *Panel Discussion* **Understanding the Standards Setting Process: How Things Work**
This panel discussion will describe the processes and timelines of the various standards setting organizations and identify some of the key realities facing public health and health services research as they begin to engage in these processes.
Karen Trudel, Health Care Financing Administration
Jan Root, Utah Health Information Network
Ed Hammond, Duke University Medical Center
George Arges, American Hospital Association
Jean Narcisi, American Medical Association
Eileen Salinsky, The Lewin Group (moderator)

Noon – 1:00 pm **Lunch**

1:00 pm – 3:00 pm *Break-out Sessions*	**Ensuring Effective Representation in Standards Maintenance Efforts and Promoting Widespread Participation in These Efforts** These break-out sessions will seek to design strategies for (1) maintaining representation on the standards committees, (2) ensuring that this organized input is broadly reflective of public health and research concerns, and (3) identifying responsible parties.
3:00 pm – 3:15 pm	**Break**
3:15 pm – 5:00 pm	**Reviewing Workshop Results** This concluding session will recap the major recommendations that emerged during workshop proceedings, identify unresolved issues, and clarify next steps.

APPENDIX C

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APPENDIX D

Web Sites for Administrative Simplification

1. Centers for Disease Control and Prevention: Proposed CDC Health Data Standards -- http://www.cdc.gov/data/index.htm
2. National Center for Health Statistics (general): http://www.cdc.gov/nchswww/
3. National Committee on Vital and Health Statistics (general): http://aspe.os.dhhs.gov/ncvhs/
4. Office of the Assistant Secretary for Planning and Evaluation – State Level Data Integration: http://aspe.os.dhhs.gov/statereg/
5. Agency for Health Care Policy and Research (data and surveys – specific info for standards): http://www.ahcpr.gov:80/data/
6. Department of Health an Human Services (Data Council): http://aspe.os.dhhs.gov/datacncl/index.htm
7. Health Care Financing Administration

   http://www.hcfa.gov/regs/hipaacer.htm
8. Health Care Financing Administration – links to other websites with info on administrative simplification): http://www.hcfa.gov/medicare/edi/hipaaedi.htm; also see the HIPPA home page at http://www.hcfa.gov/hipaa/hipaahm.htm
9. Massachusetts Health Data Consortium, Inc (general – has HIPPA section, compliance info etc): http://www.mahealthdata.org/
10. Data Interchange Standards Association: http://www.disa.org/
11. National Uniform Claim Committee: http://www.nucc.org/
12. National Uniform Billing Committee: http://www.nubc.org/
13. National Association of County and City Health Officials – program on data sharing:

    http://naccho.org/projects/data_all.html
14. Centers for Disease Control and Prevention – Integrated Health Systems:

    http://cdc.gov/funds/invest7.htm#xiii
15. National Association of Health Data Organizations:

    http://www.nahdo.org
16. Workshop on Electronic Data Interchange (WEDI):

    http://wedi.org
17. Health Level 7 Standards:

    http://www.mcis.duke.edu/standards/HL7/hl7.htm
18. Accredited Standards Committee (ASC) X12:

    http://www.disa.org/